

Sexual Orientation & Gender Identity: Demographic Data Collection Q&A Summary

#	Question	Answer(s)
1	Why is Gender non-binary not also included in the line item with Gender queer?	<p>Poshi Walker: Counties <i>can</i> always include gender non-binary as part of their list.</p> <p>Dr. Brian Sala: The <i>reporting</i> requirement to MHSOAC specifies certain categories. That does not preclude any County from using additional terms, but it does require the County to think through a mapping from those additional terms to the required reporting categories. We encourage Counties to use terminology that fits its population, but to think through mapping those additional terms to the required reporting categories.</p>
2	Can you provide clarity on how to report the required unduplicated count of individuals served if demographics are meant to be collected anonymously? Or does this mean that the demographics should be kept confidential?	<p>Poshi Walker: Demographic data, yes, is supposed to be anonymous - that is not always the case. There are ways of putting initials and numbers so that you <i>can</i> enter that, and it is still anonymous, but you can still match if you have the same person filling out a demographic data form over and over again. It is not my understanding that the demographic data be unduplicated.</p> <p>Dr. Brian Sala: The reporting requirement to the OAC is to provide aggregated numbers by the reporting categories. If aggregated numbers in a reporting category fall below threshold numbers, or if the County has significant concerns about protecting the privacy of individuals' data, it is required in the regulations to submit a separate report marked "Confidential" so that the OAC, in its reporting of Statewide information, ensures that it appropriately aggregates those small numbers with other reporting categories or with other Counties' data. The purpose is to protect the privacy of individuals. There are rule of thumb standards for testing data to see whether there is a significant risk of re-identification of individuals when you have small cell sizes. The usual rule of thumb is if there are less than 11 individuals in a specific reporting category. Additionally, there is a rule of thumb test for the denominator, addressing how many <i>could</i> have been served in a reporting category, which is 20,000 or less. Counties may be deterred from publishing a demographic report for many demographic categories because of concerns about protecting the privacy of individuals, and the regulations provide for that. But the expectation is that the Counties will then provide a separate report to the OAC marked "Confidential" with the full information in the reporting categories.</p>
3	Why is intersex not included as a sex?	<p>Rory O'Brien: Intersex is not currently included as a sex in the regulations; that does not preclude counties (as with the sexual orientation or gender identity question) from adding that category to the list and deciding on their own to offer intersex as a category. If that is something indicated in your Counties, then there is the flexibility & freedom to do so. However, it is not a regulation reported category to the OAC, largely because under California law & the OAC regulations, intersex is not, and still remains not, a sex assigned at birth. Under California law, as of January 2019, people can alter their birth certificate to have an "X" instead of an "M" or "F." However, babies in California are not yet being born with an intersex marker on their birth certificate; it is something that is amended to a birth certificate. There is indication that we are still developing how best to ask about intersex identity. There is some evidence of false positives when asked alongside "male" & "female," meaning people are clicking on "intersex" when they may not be intersex. The recommendations out of the Williams Institute that are still in development is that that question "Sex assigned at birth" be followed by another one that essentially asks, "What is your intersex diagnosis?" That is a verification to weed out false positives; however, that does not fall under the MHSOAC PEI and Innovation regulations. It is not something Counties need to do, but it is good to be aware, if adding intersex as a category, that you may get some false positives.</p>

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4	Some might identify as male or female, rather than transgender.	<p>Rory O'Brien: In response to the cross tabs, yes, it is 100% true. Some people may be transgender and, when given the choice to identify their current identity, they may not choose "transgender." They may choose "male" or "female," and by cross tabbing, you would be able to identify whether this was someone assigned female at birth who currently identifies as male.</p> <p>Dr. Brian Sala: The way the reporting requirements to the State are constructed is that the categories are independent, so this point is very important for local analysis. Ask those serious questions about what the purpose is. What are we trying to get done? An important part is asking serious questions at the local level of how and are we serving populations in need. The goal is to provide the right services at the right time to every individual who is in need of services. The principle built into the MHSA for stigma reduction and reduction in disparities is to drive everyone to ask serious questions about the delivery of services and whether they are being delivered at the right time, in the right place, to individuals in need of services. That should be the driving principle for all of this data collection, to query our strategies.</p> <p>Poshi Walker: On the part of advocates, there was an assumption that Counties were already cross tabbing their data. When we advocated for the 2 part question, which is "Sex assigned at birth" and "Current gender identity," we did not know Counties report these as a silo data point. We are, as advocates, at a point of going back and looking at demographic data in general and how useful it is to just have silo data. It really does not necessarily make sense to ask the two (2) part question if it is not being analyzed the way it was meant to be.</p>
5	Are the following terms appropriate in your opinion: Trans Male/FTM and Trans Female/MTF?	<p>Rory O'Brien: Yes, they can be appropriate if indicated by your population. If you find that these are terms used by the populations you serve, then you should include them as categories. The more general bucket category to these two (2) categories, for reporting purposes, would be "transgender," but many Counties already split out "transgender" into "trans male" and "trans female" options. You are welcome to have a backslash "FTM" or "MTF" if it is indicated by the populations with which you work. "trans male/FTM" and "trans female/MTF" are culturally specific terms, as are most categories under the regulations, so they do not necessarily mean the same thing from one (1) community to the next. There is not a huge regional difference across California in the use of these terms, but it is something to keep note on.</p>
6	Does Marin County have policies and procedures in place on how to collect this data/ask these questions?	<p>Dr. Jei Africa: We have not. I would suggest contacting the San Mateo County Pride Center. Lisa Putkey is their Program Director, and she has helped develop these protocols & policies with FAQs that is being used at the Pride Center. The forms they use are expansive (i.e. more terms) and aligned with what the local community wanted but is mapped with County forms per regulation. Doris Estremera is the County contact. Our goal in Marin is to develop something over time.</p>
7	Is a short disclaimer a good idea before asking these types of questions? For example, "The next few questions can be personal. We ask this to have as much information about you that could help us serve you better. You are not required to answer."	<p>Rory O'Brien: We recommend that demographic data be asked on paper or tablet, such that a disclaimer ahead of the questions is unnecessary. We also would not recommend a short disclaimer ahead of the sexual orientation and gender identity questions in particular because all demographic questions are personal, and providing a short disclaimer directly before the sexual orientation and gender identity questions indicates a sense that those questions are particularly personal more so than, for example, income. There is a very low refusal rate for these questions. There are certainly culturally specific barriers, but people are generally okay answering these questions, and it is not an issue. So a short disclaimer would not be necessary.</p>

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8	<p>What do you recommend saying to clients who are angry that intersex is not an option for birth sex?</p>	<p>Rory O'Brien: Being able to provide information on why the current categories are asked, empathizing with their anger, and looking into options to address it for the County going forward are all ways of having your clients be heard. Following through and reporting back to that client what you have learned in bringing their concerns forward are also important to do.</p> <p>Dr. Jei Africa: We have encountered many of these instances. It is really important to prepare the staff, or whoever is going to ask these questions, some example responses to what clients or family members may ask. A local hospital we worked with started asking these questions, and there were some clients during registration asking, "Why are you asking those questions?" We did not prepare staff for the possible push-back or feelings or questions that the clients might be asking, which created challenges and confusion. But during the second iteration of the training, we prepared staff with FAQs and possible responses. We also gave resources to first-line staff. We told them that there will be people who will question you, challenge you, and argue with you. But there will also be folks who say, "I'm glad you are asking that question." Creating and coming up with solutions like this helps prepare staff for difficult conversations they might encounter.</p> <p>Poshi Walker: This is why we want to talk about the difference between demographic data and clinical data. It is very different reading a paper form or being handed a tablet where your name is not associated with your responses, where you are just checking off boxes and deciding to skip certain questions, versus having a human being who maybe you do not know, and this is the first time you have met them, and they are asking personal questions such as, "Are you divorced? What is your age? How much money do you make? Do you have children?" along with sexual orientation and gender identity. People can skip over items on a form. It is different when they have to face another human being and answer that question. Studies about asking sexual orientation and gender identity questions for demographic data collection have been done with the assumption that it was being collected anonymously on a piece of paper or on a tablet, and not being asked face-to-face by another human being.</p>
9	<p>Q for OAC: Can we add non binary to the genderqueer category or do we have to keep it as a separate category?</p>	<p>Dr. Brian Sala: Have the discussion at the local level on what the appropriate terms are for your populations, and then for reporting purposes, map the terms you are using back to the minimum required reporting categories. There is an option in the regulations under 3560.010(a)(6) that says Counties may report any other data the "County considers relevant, for example, data for additional demographic groups that are particular prevalent in the County, at elevated risk of or with high rates of mental illness, unserved or underserved, and/or the focus of one or more Prevention and Early Intervention funded services." There is a great deal of flexibility at the local, County level for reporting what you believe is relevant for your local purposes. The structure of the required reporting categories is to ensure as best as possible some reasonable uniformity across the state so that the OAC is able to do Statewide reporting and provide feedback at the local level, but it should not preclude you from reporting things that you believe locally are of importance.</p> <p>Poshi Walker: From a collecting point of view, I do not see anything wrong with "genderqueer/non-binary" and putting it all on one line. It might help people realize that is where they fit.</p> <p>Dr. Brian Sala: We welcome feedback on how the regulations can be refined and improved over time. There is nothing that stops us from considering further amendments to the regulations where there is a clear justification, need, and desire to make those modifications.</p>

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10	Does state expect demographics to be provided for each individual so that it can be cross-tabulated or is it ok to summarize counts for each demographic category?	Dr. Brian Sala: The regulatory requirement is for <i>aggregated</i> reporting by program and specified demographic category, not for individual level data. There are those in the OAC & other stakeholder organizations who recognize the value in the State receiving individual-level data, but that is not a current requirement of the regulations.
11	When we add an additional category but aren't expected to report the data, does this mean there will be gaps in your report? (i.e., your data won't add up to the total number of participants?)	<p>Dr. Brian Sala: The OAC recommends each County use terms in their data collection that are relevant and useful at the local level, but that you have a protocol for mapping from those terms to the required reporting categories. There may be some variation in how those terms are understood from location to location. This is a local matter to think through mapping from how individuals feel most comfortable responding to the reporting categories.</p> <p>Poshi Walker: Technical assistance from people such as Rory, myself, and Jei might be helpful in knowing what the appropriate bucket would be. I recommend you add this in your report so the OAC can see your methodology. If they see Counties are, for example, putting pansexual in the "another" sexual orientation category, but many other Counties are putting pansexual under "bisexual," then we may need to give instruction on where pansexual should go so that the data becomes more accurate across the State.</p>

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12	What do you recommend saying to clients who are offended over being asked about gender identity and sexual orientation?	<p>Rory O'Brien: Listen to their concerns and make it clear that we ask this question of everyone who comes in the door. They are welcome to answer it or not, and it is up to them. Hear their concerns. There is less risk of people being offended if they are asked on paper than by a human being. It is easier for them to look at it and say, "This makes me uncomfortable or upset, and I am just going to skip it." There are some people who will read it on paper and bring it to your desk and say, "Why are you asking me this?" That is an opportunity to be empathetic and hear their concerns, and to make it clear you ask everyone, and that it is not a mandated question.</p> <p>Poshi Walker: Think of what you would do with a client who was, for example, upset you asked them their race because they obviously appear white? I do not think we are as afraid of somebody's anger over that because we are more used to asking racial and ethnic questions. So how would you handle a client who is upset about being asked any demographic question? I was always upset when asked to check whether or not I had been divorced, because I thought, "Why do you need to know that?" So think of it that way, rather than specifically to sexual orientation or gender identity.</p> <p>Dr. Jei Africa: The San Mateo Pride Center has done a lot of training and even role playing to address what to say when asking these questions. Income, for example, may be a personal thing, or immigration status. It is really important to consider what the same response would be, or with race, ethnicity, SES, or marital status. We are trying to understand who the people we are seeing are. These are questions that have not been typically asked before, and now we are very interested in the population we are serving, which will eventually help in program development or client care.</p> <p>Dr. Brian Sala: It is important to try to put some context around the data collection, and that is an important piece of training for your staff, to try to provide context to respondents. Why are we asking these questions? We are asking these questions of everyone. It is not that a staff member has preemptively identified you as a member of a special population, and therefore we are only asking because we think you identify as LGBTQ; rather, we are trying to ask every participant, every client, this panel of questions because we are trying to develop a stronger understanding of the populations being served so that we can then get to the more important question of what the population in need of services is and how we design strategies to drive doing a better job of delivering services where and when they are needed.</p>
13	I'm wondering if the MHSOAC would develop an online SOGI webinar that counties could use to train line staff so we don't end up making mistakes that others have already made. Is this a possibility?	<p>Dr. Brian Sala: We are going to work towards how we can resource that, work with our contract holders and other stakeholders and Counties to think through how we can best design material to be supportive.</p>

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14	How specifically will SOGI data be analyzed at a county and state level to improve quality of care and access to services for queer and trans clients?	<p>Dr. Brian Sala: An important use of this data is at the local level to better understand your own service population and think through your own population of need. At the State level, we are trying to utilize these aggregate reports to build a picture of statewide service delivery and to compare that against standards of expectation for the population of need. This is an opportunity for us as a central service provider to aggregate data across many programs and many counties and try to identify patterns that can reveal systematic information about service delivery across the State. The purpose is to drive conversations. What are we trying to get done? How are we doing? How do we know if we are delivering services in a way that is leading toward stigma reduction and reduction in disparities? Are we are delivering the right services at the right time to individuals who are in need of those services?</p> <p>Poshi Walker: The very first time that sexual orientation and gender identity data of any kind was collected across the age spectrum throughout California was through these PEI regulations. After that came AB959, which required more agencies and programs to collect that data. Sexual orientation and gender identity, unlike other categories, are not collected on a census or statewide level. You can say, for example, that your County is 30% African American because of the US Census, but you do not know how many people in your Counties are lesbian, gay, bisexual, transgender, queer, questioning, etc., because nobody really collects that data, and anybody that tells you they know how many LGBTQ people live in a place are often times giving an educated guess. So this is the first step, and when you know that there is a population that exists, then you can provide programming and funding. If, for example, we did not collect data on African Americans, we would not know that they are overrepresented in the prison system, and then we could not address that disparity. We would not know languages people speak if we did not collect that information. So from a very top level, that is what this is going to do. The difference between demographic and clinical data is the data you have connected to each individual person, and where it is connected to an individual with a name, etc. That is where you might be able to look at local quality of care based on individual categories so that everything can be cross tabulated. From a higher, statewide level and overall County level, this was the first time we were ever going to get a chance to see if we even exist anywhere. There are places that say, "We do not have programs here because there are not any queer people that live here," when we know that there were. So this is an opportunity to make the invisible visible.</p>
15	Is there a tool or app that you can recommend or that the OAC has developed for collecting demographic information via a tablet or smartphone device?	<p>Kara Chung: We do not have anything like that implemented at this time. We are considering a PEI toolkit to provide a possible template for Counties that would include standardized demographic questions, so that is something we currently are considering.</p> <p>Rory O'Brien: This is an innovative idea that could possibly be brought into a community planning process in your County.</p> <p>Dr. Brian Sala: Counties may even consider collaborating with other Counties through, for example, CalMHSA or other joint strategy.</p>

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16	<p>One of the only ways we can think of to easily capture referral and linkage data is to store their demographic data on intake so that when they are eventually referred or linked, you don't have to ask the same demographic questions again. However, this results in a sort of EHR or non-anonymous data. So, what is the best way to capture demographic data across the referral spectrum?</p>	<p>Poshi Walker: Demographic data, which you are required to report to the OAC, may be very different than clinical data, and that would not necessarily stop you from also making that report. For referrals to see, for example, if a certain population is coming to one (1) appointment and never coming back, or to see if a certain population is sticking with services or hopping from program to program – that would be more like clinical data and not the overarching question of “How many people live here? How many people of “x” demographic access our services?” I do see a difference and I do see a place in the EHR, but that is a different question from why, when, and how you are asking, and what you really want to know from the person, and if there is an opportunity to identify changes later. So if they do not come out right away, what happens if they come out later or while going through the program? What if this is something they discover about themselves? That is a very different process than demographic data you ask anonymously at the beginning.</p> <p>Dr. Jei Africa: In regards to some of the outreach and engagement data: Some Counties ask, “Did you refer somebody? Was there any referral based on this outreach event?” There is a difference between who is attending, demographically, versus asking them why they need to be referred elsewhere or asking about clinical care. There is more conversation that needs to happen. There is a difference between demographic data and data that will help an individual get the most appropriate resources. I would want to know what specific kind of information you are asking in terms of referral and linkage. So if, for example, someone comes to a booth and asks what the LGBTQ centers are, that is different than saying “Sacramento has this, San Mateo has this, and San Francisco has this.” That is something very different than a person telling you, “I am asking because I have a brother who wants more information to seek services.”</p>
17	<p>We currently give the demographics questions on paper. People will often ask what a word means or how to answer a question. I don't want to influence anyone's answer by the way I respond, or the words I use, so I usually say something along the lines of, "If you don't know the word, it is probably not a way you define yourself, but it's ok not to answer if you don't know or don't feel comfortable with any of the options." Is there a better way to respond so that we can collect more information?</p>	<p>Rory O'Brien: That response is not wrong. A number of times I have been in conversation with LGBTQ people who are still perhaps on the path to settle how they want to define or describe themselves,” and I have heard LGBTQ people say, “I have never heard that term before; that is me.” It is positive and powerful as a clinician to say, “That is a great question, and this is how I have heard ‘genderqueer’ described in the past.” That is an opportunity you can take, if it is one you have the cultural knowledge of to answer accurately. If you do not, then this quote works fine. But if you are in a position to have the knowledge to support your client’s empowerment and expand their understanding of our world, then please do use that opportunity.</p> <p>Dr. Jei Africa: It depends on whether it is just demographic data collection or more related to clinical care. So in circumstances where you have the knowledge, I agree, you can explain that. I often err on the side of whether it is appropriate. If it is a teaching opportunity and you are confident that you can explain it, I would do it. We have a role of demystifying and creating opportunities for people to understand these issues. One of the institutions I have helped responds with, “This might be a question you want to ask a provider, and it may pertain to you or not.” The reason we say that is we want to generate a conversation, even with cis-gender or non-LGBTQ folks. I engage people in a conversation depending on appropriateness. That is a great opportunity to have a conversation to help people understand why we are asking these questions. In certain instances, our first-line staff say, “We would be happy to tell you more, and you can ask your provider as you come into the clinic or appointment.” This has been valuable in demystifying & educating clients and family members.</p>

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18	In follow-up, this is a regulatory issue. We are being asked to use demographic data to measure who is being referred and linked to service.	<p>Dr. Brian Sala: This most specifically refers to Access and Linkage to Treatment Programs & Improve Timely Access to Services Programs, both of which specify expectations that Counties report number of individuals being referred & number of individuals who followed through on those referrals by demographic categories as well as overall, and this we recognize as a very challenging expectation, both because of the nature at the front end of referring programs. It may be the case this is a program that does not typically engage more than once or repeatedly with individuals, so this is a very high expectation that you would collect very detailed demographic information even though you are only interacting with an individual once. I do not think there is any expectation from the State that a light-touch program that are only cursory interacting with individuals would be expected to collect detailed demographic on every individual, but the goal would be to understand the efficacy of these programs. So the goal should be to have a better understanding of how these programs are interacting with individuals who are identified as desiring or in need of services and how effective County programming is in encouraging the completion of a referral to actually connecting individuals with needed services. I would encourage every County to think about, for example, survey strategies on the front end and then more intensive data collection strategies on the completion end for individuals who show up and are linked to services and participate in a clinical program in particular. There is an opportunity to collect more detailed demographics and ask questions about whether and how they learned about the program. The OAC is not primarily an enforcement agency. This data collection is primarily about gathering and sharing useful information back to the Counties and providers to better understand how well they are doing, whether there are patterns of deficiency in who is being served, how and when, and identifying strategies for improving the quality of service and the success with which Counties and providers are meeting and providing the right services at the right time to individuals who need them. Think hard about what we are trying to get done. Be open about the challenges of collecting appropriate data and think about strategies for meeting the goals of data collection, particularly on the front end. We do want to understand what works and what does not work in Access and Linkage to Treatment Programs. We do want to understand where there is a need for more innovative approaches in reaching hard to reach populations, and if we do not ask these questions, we are going to have a difficult time developing best practices and sharing best practices across the State.</p>